Response To Scottish Government's Consultation On Proposals For Reform Of The Adults With Incapacity Act 2000 (April 2018)

Response ID ANON-3GJP-753H-U

Submitted to **Adults with Incapacity Reform**
Submitted on **2018-04-30 12:51:57**

Chapter 1 - Background, current law and glossary of terms

Chapter 2 - Summary of proposals

Chapter 3 - Restrictions on liberty

Do you agree with the overall approach taken to address issues around significant restrictions on a person's liberty?

Not Answered

Please explain your answer.:

In particular we are suggesting that significant restrictions on liberty be defined as the following;

Not Answered

Please give reasons for your answer.:

Are there any other issues we need to consider here?

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Chapter 4 - Principles of Adults with Incapacity legislation

Do you agree that we need to amend the principles of the AWI legislation to reflect Article 12 of the UNCRPD?

Not Answered

Please give reasons for your answer.:

Does our proposed new principle achieve that?

Not Answered

Please give reasons for your answer.:

Is a further principle required to ensure an adult's will and preferences are not contravened unless it is necessary and proportionate to do so?

Not Answered

Please give reasons for your answer.:

Are there any other changes you consider may be required to the principles of the AWI legislation?

Not Answered

Please give reasons for your answers.:

Chapter 5 - Powers of attorney and official supporter

Do you agree that there is a need to clarify the use of powers of attorney in situations that might give rise to restrictions on a person's liberty?

Not Answered

Not Answered

Please give reasons for your answer.:

Is there a need to clarify how and when a power of attorney should be activated?

Not Answered

If you have answered yes and have views on how this should be done, please comment here.:

Do you think there would be value in creating a role of official supporter?

Not Answered

If you have answered yes, please give us your views on how an official supporter might be appointed.:

Countries that have created a role of supported decision maker have used different names, such as supportive attorney in Australia, or a 'Godman in Sweden, meaning custodian. We have suggested 'official supporter'. Do you think this is the right term?

Not Answered

If you selected 'Prefer another term', please give details.:

Chapter 6 - Capacity assessments

Should we give consideration to extending the range of professionals who can carry out capacity assessments for the purposes of guardianship orders?

Not Answered

If you answered yes, can you please suggest which professionals should be considered for this purpose?:

Chapter 7 - Graded guardianship

Do you agree with the proposal for a 3 grade guardianship system?

Not Answered

Please give reasons for your answer.:

Our intention at grade 1 is to create a system that is easy to use and provides enough flexibility to cover a wide range of situations with appropriate safeguards. Do you think the proposal achieves this?

Not Answered

Please give reasons for your answer.:

Are the powers available at each grade appropriate for the level of scrutiny given?

Not Answered

Please give reasons for your answer.:

We are suggesting that there is a financial threshold for Grade 1 guardianships to be set by regulations. Do you have views on what level this should be set at?

We are suggesting that there is a financial threshold for Grade 1 guardianships to be set by regulations. Do you have views on what level this should be set at? :

We are proposing that at every grade of application, if a party to the application requests a hearing one should take place. Do you agree with this?

Not Answered

Please give reasons for your answer.:

We have listed the parties that the court rules say should receive a copy of the application. One of these is 'any other person directed by the sheriff'. What level of interest do you think should be required to be an interested party in a case?

What level of interest do you think should be required to be an interested party in a case?:

We have categorised grade 3 cases as those where there is some disagreement between interested parties about the application. There are some cases where all parties agree however there is a severe restriction on the adult's liberty. For instance very isolated and low stimulus care settings for people with autism, or regular use of restraint and seclusion for people with challenging behaviour. Do you think it is enough to rely on the decision of the sheriff/tribunal at grade 2 (including a decision to refer to grade 3) or should these cases automatically be at grade 3?

Do you think it is enough to rely on the decision of the sheriff/tribunal at grade 2 (including a decision to refer to grade 3) or should these cases automatically be at grade 3?:

Please add any further comments you may have on the graded guardianship proposals.

Please add any further comments you may have on the graded guardianship proposals.:

Do you think our proposals make movement up and down the grades sufficiently straightforward and accessible?

Not Answered

Please give reasons for your answer.:

Do you agree with our proposal to amalgamate intervention orders into graded guardianships?

Not Answered

Please give reasons for your answer.:

Do you agree with the proposal to repeal Access to Funds provisions in favour of graded guardianship?

Not Answered

Please give reasons for your answer.:

Do you agree with the proposal to repeal the Management of Residents' Finances scheme?

Not Answered

Not Answered

Please give reasons for your answer.:

Chapter 8 - Forum for guardians

Do you think that using OPG is the right level of authorisation for simpler guardianship cases at grade 1?

Not Answered

Please give reasons for your answer.:

Which of the following options do you think would be the appropriate approach for cases under the AWI legislation?

Not Answered

Please give reasons for your answer.:

Please also give your views on the level of scrutiny suggested for each grade of guardianship application.

Please also give your views on the level of scrutiny suggested for each grade of guardianship application.:

If you have any further comments on the proposals for the forum, please add them here.

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Chapter 9 - Supervision and support for guardians

Is there a need to change the way guardianships are supervised?

Not Answered

If your answer is yes, please give your views on our proposal to develop a model of joint working between the OPG, Mental Welfare Commission and local authorities to take forward changes in supervision of guardianships.:

If you consider an alternative approach would be preferable, please comment in full.

If you consider an alternative approach would be preferable, please comment in full.:

What sort of advice and support should be provided for guardians?

What sort of advice and support should be provided for guardians?:

Do you have views on who might be best placed to provide this support and advice?

Not Answered

Please give reasons for your answers.:

Do you think there is a need to provide support for attorneys to assist them in carrying out their role?

Not Answered

If you answered yes, what sort of support do you think would be helpful?:

Chapter 10 - Order for cessation of residential placement, short term placement order

Do you agree that an order for the cessation of a residential placement or restrictive arrangements is required in the AWI legislation?

Not Answered

If so, does the proposal cover all the necessary matters?:

Do you agree that there is a need for a short term placement order within the AWI legislation?

Not Answered

Please comment as appropriate.:

Do you consider that there remains a need for section 13ZA of the Social Work (Scotland) Act 1968 in light of the proposed changes to the AWI legislation?

Not Answered

Please give reasons for your answers.:

Chapter 11 - Advance directives

Should there be clear legislative provision for advance directives in Scotland or should we continue to rely on common law and the principles of the AWI Act to ensure views are taken account of?

Yes

Please give reasons for your answer.:
As acknowledged in this consultation document, the reliance of Scottish Government on the courts and the common law to develop this area of law has not been productive. This is because there is simply not the volume of cases coming through the Scottish courts to generate clear precedents on advance decisions, or to bring clarity where there is none in the common law, e.g. on what precisely must be done by an adult to signal a lawful advance decision. While we do not believe that a statutory regime would resolve all issues, it would at least provide a framework for Scottish citizens and professionals in the following respects:

1. It would address the qualifying criteria for which statements or actions amounted to advance decisions that carry the force of law, including the necessary standard of proof;

2. It would provide a single source of reference when people are drafting crucial life documents, such as wills, to guide their actions and advice given to them on their final wishes. It may be noted that advance directives represent one of several important ways that people come into contact with the legal system, and they may do so when they are at their most vulnerable. As such, it represents a core ‘access to justice’ gateway, which makes clarity and simplicity particularly important;

3. Perhaps most importantly, it could - and should - provide mechanisms for resolving disputes over putative advance decisions. Such disputes between relatives of an adult with incapacity and health care professionals seeking to act in a patient’s best interests are not uncommon. We should not imagine that the absence of case law is any indication that such disputes do not arise (or that they are adequately resolved). It is trite to point out that court action is costly and lengthy. A legislative framework that included a clear channel for dispute resolution would be invaluable in this regard.

For these reasons, we support the move to a legislative basis for advance decisions in Scotland.

If we do make legislative provision for advance directives, is the AWI Act the appropriate place?

Yes

Please give reasons for your answers.:
We see no reason why provisions should not be included in any revision to the Adults with Incapacity (Scotland) Act 2000, although the means of incorporation is not the focus of our response.

Chapter 12 - Adjustments to authorisation for medical treatment

Do you agree that the existing s.47 should be enhanced and integrated into a single form?

Not Answered

Please give reasons for your answer.:

Do you think that there should be provision to authorise the removal of a person to hospital for the treatment of a physical illness or diagnostic tests?

Not Answered

Please give reasons for your answer.:

Do you agree that a 2nd opinion (medical practitioner) should be involved in the authorisation process?

Not Answered

Not Answered

Please give reasons for your answer.:

Do you agree that there should be a review process every 28 days to ensure that the patient still needs to be detained under the new provisions?

Not Answered

How many reviews do you think would be reasonable?:

Do you think the certificate should provide for an end date which allows an adult to leave the hospital after treatment for a physical illness has ended?

Not Answered

Please give reasons for your answer.:

In chapter 6 we have asked if we should give consideration to extending the range of professionals who can carry out capacity assessments for the purpose of guardianship orders. Section 47 currently authorises medical practitioners, dental practitioners, ophthalmic opticians or registered nurses who are primarily responsible for medical treatment of the kind in question to certify that an adult is incapable in relation to a decision about the medical treatment in question. It also provides for regulations to prescribe other individuals who may be authorised to certify an adult incapable under this section. Do you think we should give consideration to extending further the range of professionals who can carry out capacity assessments for the purposes of authorising medical treatment?

Not Answered

Please give reasons for your answers.:

Chapter 13 - Research

Where there is no appropriate guardian or nearest relative, should we move to a position where two doctors (perhaps the adult with incapacity's own GP and another doctor, at least one of whom must be independent of the trial) may authorise their participation, still only on the proviso that involvement in the trial stops immediately should the adult with incapacity show any sign of unwillingness or distress?

Yes

Please give reasons for your answer.:
The full context of the Mason Institute's response to Chapter 13 of this consultation is set out in response to the final question: 'Should Part 5 of the act be made less restrictive?'. This position underpins our responses to each of the consultation questions within this Chapter.

As described under the final question below, we support a move towards an approach that focuses on inclusion of adults in research (whether they lack capacity or not), wherever this can be done responsibly and without incurring disproportionate risks.
We therefore broadly support the implementation of safeguarding mechanisms – such as that described in this question – where this will facilitate the responsible involvement of a wider category of participants in health research.

We agree that careful consideration should be given to avoiding actual or apparent conflicts of interest, such as between those who authorise participation in research and those who safeguard participants.

We note that this consultation question refers to "trials" (presumably referencing clinical trials). For the reasons set out under the final question below, we consider that by focussing on this aspect of heath research, this fails to appreciate the breadth of the modern research landscape. For completeness, we further note also that the current Clinical Trials Directive is to be replaced by the Clinical Trials Regulation EU No 536/2014, the adoption of which in the UK remains unclear in light of Brexit.

When drafting their power of attorney should individuals be encouraged to articulate whether they would wish to be involved in health research?

Yes

Please give reasons for your answer.:
The full context of the Mason Institute's response to Chapter 13 of this consultation is set out in response to the final question: 'Should Part 5 of the act be made less restrictive?'. This position underpins our responses to each of the consultation questions within this Chapter.

As described under the final question below, we support a move towards an approach that focuses on inclusion of adults in research (whether they lack capacity or not), wherever this can be done responsibly and without incurring disproportionate risks.

In principle, we therefore agree that when drafting their power of attorney, individuals should be encouraged to articulate whether they would wish to be involved in health research. However, while this might be helpful as a general approach, particularly to the person who subsequently discharges the power of attorney, we would urge caution in relation to viewing this as a complete solution. While stating a preference in a power of attorney may be one way to indicate willingness to participate in health research, this must not preclude other routes to participation. There are a number of further issues raised by use of a power of attorney. These include, but are not limited to: how the power of attorney is worded and explained to the potential participant; fluctuation in the capacity of the potential participant; the application of the AWI (Scotland) Act, which might, in any event, frustrate the potential participant's willingness to be involved in health research.

Should there be provision for participation in emergency research where appropriate (e.g. if the adult with incapacity has suffered from a stroke andthere is a trial running which would be likely to lead to a better outcome for the patient than standard care)?

Yes

Please give reasons for your answer.:
The full context of the Mason Institute's response to Chapter 13 of this consultation is set out in response to the final question: 'Should Part 5 of the act be made less restrictive?'. This position underpins our responses to each of the consultation questions within this Chapter.

As described under the final question below, we support a move towards an approach that focuses on inclusion of adults in research (whether they lack capacity or not), wherever this can be done responsibly and without incurring disproportionate risks.

We therefore broadly support the suggestion that provision should be made for participation in emergency research where this will facilitate the responsible involvement of a wider category of participants in health research.

Again, we note that this consultation question refers to "trials" (presumably referencing clinical trials). For the reasons set out under the final question below, we consider health research as having a wide remit, and to frame such considerations exclusively within the clinical trials paradigm does not reflect the breadth of the modern research landscape.

Should authorisation be broadened to allow studies to include both adults with incapacity and adults with capacity in certain circumstances?

Yes

Please give reasons for your answer.:
The full context of the Mason Institute's response to Chapter 13 of this consultation is set out in response to the final question: 'Should Part 5 of the act be made less restrictive?'. This position underpins our responses to each of the consultation questions within this Chapter.

As described under the final question below, we support a move towards an approach that focuses on inclusion of adults in research (whether they lack capacity or not), wherever this can be done responsibly and without incurring disproportionate risks.

We understand this question to relate to the current wording of s.51(1)(a) of the Act which provides (in summary) that where research of a similar nature can be carried out on an adult with capacity it shall not be carried out on an adult without capacity.

We consider that the current drafting is problematic, in that, due to its binary nature, it might serve to exclude adults with incapacity from research without consideration of the nature or context of that research. We therefore consider that this foundational drafting should be reviewed, before steps are taken to draft additional criteria that would allow for studies that involve a cohort including both adults with and without capacity. However, with this caveat, we do envisage that there may very well be research that could be carried out responsibly and without disproportionate risks to such a cohort.

Should clinical trials of non-medicinal products be approached in the same way as clinical trials of medicinal products?

Not Answered

Please give reasons for your answer.:
The full context of the Mason Institute's response to Chapter 13 of this consultation is set out in response to the final question: 'Should Part 5 of the act be made less restrictive?'. This position underpins our responses to each of the consultation questions within this Chapter.

As described under the final question below, we support a move towards an approach that focuses on inclusion of adults in research (whether they lack capacity or not), wherever this can be done responsibly and without incurring disproportionate risks.

We are not clear what is envisaged by the scenario described in this question. However, we note that there is evidence that the current legislation has been

developed in a piecemeal fashion, for example with the addition of provisions for clinical trial research, as inserted at 51(3A). We would suggest that this review of the legislation provides the opportunity to consider its operation more holistically, against the backdrop of the modern research landscape, as set out more fully in our response to the final question below.

Should there be a second committee in Scotland who are able to share the workload and allow for appeals to be heard respectively by the other committee?

Yes

Please give reasons for your answer.:
The full context of the Mason Institute's response to Chapter 13 of this consultation is set out in response to the final question: 'Should Part 5 of the act be made less restrictive?'. This position underpins our responses to each of the consultation questions within this Chapter.

As described under the final question below, we support a move towards an approach that focuses on inclusion of adults in research (whether they lack capacity or not), wherever this can be done responsibly and without incurring disproportionate risks.

Without sight of evidence of the existing ethics committee's actual workload, we consider that, in principle, there are good reasons for a second committee in Scotland, including: avoiding conflicts; providing an appeals process; speeding up the review of applications; and allowing for locating the second committee so as to provide more comprehensive geographic coverage of Scotland, particularly in locations where health research is regularly conducted.

However, this will need to be balanced against real challenges a second committee will bring, including: the need to preserve and distil the expertise that resides within the existing committee; ensuring consistency in processes and outcomes; and avoiding either a "postcode lottery" or "shopping around" for favourable opinions. This said, we note the ongoing work of the Research Ethics Service in Scotland and the Health Research Authority to maintain high levels of consistency and quality across NHS research ethics committees.

Should part 5 of the act be made less restrictive?

Yes

Please give reasons for your answer. :
In our response to this consultation, we have focused on the two topics to which the Mason Institute is able to contribute the greatest expertise and most value. These are:

• Advance Directives (Chapter 11), and
• Research (Chapter 13).

Chapter 13: Research

The following statement provides the context for all of our responses to the consultation questions relating to Chapter 13 of the consultation / s.51 of the Act.
Position statement on inclusion of adults with incapacity in research:

We recognise that when this legislation was originally drafted, the (then) Scottish Executive wished to take a more protectionist approach, guarding adults with incapacity from potential exploitation and harm from research participation. We too would have endorsed this approach at the time.

However, we believe that there are four strong reasons now to revisit the protectionist approach underpinning the original legislation. These are:

(i) Scotland's accumulated experience: The research community, regulators and Scotland A REC now have two decades' of experience of governing research involving adults with incapacity. We are not aware of any evidence in this period of exploitation of adults without capacity in the health research context. Further, governance bodies are now well-equipped to recognise possible risks and the strengths of good research protocols and practices. [1]

(ii) Evolution in health research ethics: The protectionist approach embodied in the existing legislation is no longer consonant with the evolution of research ethics. Current research ethics emphasise the benefits of research participation and contribution, and that exclusion of any group itself raises concerns about injustice or harm to that group and its members. [2] This is, for example, reflected in changing norms around the inclusion of children and pregnant women in clinical research. [3] Furthermore, an approach to the avoidance of risk which omits consideration of benefits to adults with incapacity who participate in research diverges from the proportionate approach embodied in contemporary research ethics.

(iii) Changing nature of health research: The boundaries between research and treatment have become increasingly blurred. [4] Indeed health research increasingly involves population-level and data-led research, for example, large-cohort genomic studies. [5] Exclusion of adults with incapacity, therefore not only risks precluding individuals' access to innovative therapies, but may also be detrimental to research that depends on large, inclusive datasets. Further, the way that some of the consultation questions are phrased suggests that clinical trials (and the particular issues these raise) are being taken as the paradigm of health research. This is less appropriate in the modern research landscape where research is increasingly data-led, may involves social research, or where it involves the experimental use of innovative therapies with small numbers or individual patients. We consider that this review provides an opportunity to consider this legislation holistically, in circumstances where it has developed thus far in a piecemeal fashion (see, for example, the insertion of s.51(3A)).

(iv) Legislative changes elsewhere: There have been recent changes in a number of jurisdictions, including, for example, Québec, to move towards a less protectionist mode of research governance where adults with incapacity are concerned. [6] This provides evidence of a shift in approach more generally. Further, health research is increasingly an international collaborative endeavour; if Scotland wishes to contribute to international studies, consideration should be given to ensuring that our regulations are in line with those of our potential collaborators.

For these four reasons, we suggest that it is appropriate for Scotland to move towards an approach that focuses on inclusion of adults in research (whether they

lack capacity or not), wherever this can be done responsibly and without incurring disproportionate risks. This should be reflected in the language and aims of the Act. This position underpins our responses to each of the consultation questions.

References:
[1] Dove, E.S. (2017). The liminality of NHS research ethics committees: navigating participant protection and research promotion across regulatory spaces (PhD thesis, School of Law, University of Edinburgh).
[2] DuBois, J. M., et al. (2012). Restoring balance: a consensus statement on the protection of vulnerable research participants. American journal of public health, 102(12), 2220-2225.
[3] See for example, Lyerly, A. D, Little, M. O., and Faden, R. (2008) Pregnancy and clinical research: our ignorance harms mothers and babies." The Hastings Center Report 38, no. 6; Macklin, R. (2010). Enrolling pregnant women in biomedical research. The Lancet, 375(9715), 632-633; Nuffield Council on Bioethics (2015) 'Children and Clinical Research: ethical issues'.
[4] Kass N. E., et al. (2013) "The research–treatment distinction: a problematic approach for determining which activities should have ethical oversight." The Hastings Center Report 43, no 1.
[5] See, for example, The Farr Institute for Health Informatics Research, www.farrinstitute.org/; Davies, S. C. (2017) 'Annual report of the Chief Medical Officer 2016: Generation Genome'.
[6] See, for example, Article 21 of the Civil Code of Québec, which was revised in 2013. See generally Dove, E.S. and Zawati, M.H. (2015) Amendments to the Civil Code of Québec's research provisions: a legislative comment. McGill Journal of Law and Health, 8(1), 79-110.

Miscellaneous Matters

Are there any other matters within the Adults with Incapacity legislation that you feel would benefit from review or change?

Not Answered

Please give reasons for any suggestions.:

About you

What is your name?

Name:
Emily Postan and Annie Sorbie

What is your email address?

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:
Mason Institute for Medicine, Life Sciences and the Law, University of Edinburgh, School of Law

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response only (without name)

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:
Very satisfied

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:
Slightly dissatisfied

Please enter comments here.: